



# Adaptive Positioning Equipment/ Therapy Strategies for Children with Severe Developmental Delays

Presenter: Theresa Spong MED,PT, CBP

# We are going to cover

- Different types of Adaptive positioning equipment/benefits
  - Seating
  - Standers
  - Gait trainers
  - Bath seats/toilet chairs
- Building a relationship with your DME
- Building a relationship with your Insurance provider/Medicaid
- Letters of Medical Necessity
- Case study

# Adaptive Dance Resource

My name is Elliana Kim from Always Dancing Project, a 501(c)3 non-profit organization. We provide free Zoom classes for people with developmental disabilities.

(Website:

<https://sites.google.com/view/alwaysdancingproject/home>)



# Benefits of Good Adaptive Positioning

- Improves Function / allows for participation
- Promotes certain movements by providing stability proximally
- Promotes independence
- Enhances Environmental Awareness
- Prevents/slow the progression of Skeletal deformities
- Allows for interaction with peers/family
- Builds Self esteem
- Promotes Play
- Family participation
- Allows for comfort



# Benefits continued

- Improves respiratory function
- Improves cardiovascular function
- Improves digestion
- Improves health/quality of life
- Prevents skin breakdown
- Improves oral motor control
- Improves fine motor control
- Improve quality of sleep

# Adaptive Seating

- Access to the environment
- Provide enough stability for function
  - Hips/pelvis Key
  - Proximal stability for distal control
- Be flexible enough to allow for dynamic movement
- Support as much independence as possible
- Look Good!!
- Allow for ease of transporting child and be transportable by the family ( van lifts/modifications, bus transport)

Commercial products you can  
purchase on your own- usually  
not covered by  
Medicaid/Insurance



# Medical Stroller type seating





# Wheelchairs with adaptive custom seating



# Standing in a Stander

- Research shows that Weight bearing 2 hours a day can.....
    - Aid in Hip development
    - Promotes Bone Density
  - Promote vision development
  - Allows for better environmental interactions
  - Upright may improve:
    - Digestion
    - Circulation
    - Constipation
    - Respiratory function
- +We measure progress in minutes standing, physical prompts needed, how close to upright, how long they keep head up, etc... setting timers





Shown with optional sandals, sandal raisers, and tray



# Mobil Standers





# Gait Trainers

- Allow for independent or assisted movements in upright or standing position
- Allow for possibility of independent mobility
- Participation in the environment
- Motion of the body!!!











## Gait Trainer – trial -2 weeks into using this Gait trainer

Key skills learning: this tool is a bridge to building time/endurance

vision

Lifting head- holding head up

Pushing with arms -for prop sitting, belly scooting, crawling in the future

Keeping feet on floor and standing up using legs- for walking later

Something that he can do independently mom/dad don't have to hold him up to do this

Goals can be measured in time/minutes he can tolerate or hold head up or If he moves it in any direction, we can remove prompts so that he is doing more of the work with less support. This is all Progress



# Powered Mobility is AMAZING!!!!

- This would be its own workshop in the future if there is interest
- One of the most powerful motivators for children/adults

# Adaptive toilets/shower chair/bath chairs



## Beds /cribs- Sleep safe beds



There is now positioning systems  
for when children sleep in the  
night



# Durable Medical Equipment- understanding the Alphabet

- DME- Durable Medical Equipment
- ATP- Assistive Technology Professional
- LMN-Letter of Medical Necessity



# PRO Tips

- Trial equipment before buying it
- Make sure the equipment is what you want ( you have it for 3-5 years usually)
- Check your DME services- do they service what they sell???? Who is going to adjust that equipment as your child grows. Repairs?
- Ask for credentials for your ATP make sure they are certified and not the local clerk who does geriatric equipment for the pharmacy
- Therapist has to be involved to write the LMN- better if it is a therapist who knows your child and your home and routines as opposed to a wheelchair /seating clinic at a rehab center who may not know all your unique needs and only sees you for that one appointment. School therapists? Private therapist?

# What does a GREAT Letter of Medical Necessity include

- LOTS of DETAIL
- Write it as if the reader knows nothing!!! Take out the lingo and write it in functional terms- The reader is often NOT a medical professional
- Fill in ALL the spaces of their forms
- Write additional letter outside of the standard form that will clarify and illuminate the reader to why this Client absolutely needs this piece of equipment and detail each of the parts you are asking for.
- Detail your trial of any equipment- so they know this is absolutely the piece you need- include all the types/you have tried and why they failed or were not the best choice. Companies often deny based on cost and if you trialed the cheaper version and it failed they know it is not a choice
- Include social interactions/positioning considerations/ how it will prevent long term MEDICAL issues ie scoliosis, hip dislocations etc

# IF you are DENIED- what do you do

- If you are denied ask for a detailed written explanation of the denial
  - Sometimes they need more information
  - Ask where it is written in their policy and they must give you a copy of the justification of denial
  - Some Insurance companies have a standard that they do not cover bath equipment of any kind
  - Some companies state that standers have no medical value- get research papers and send to them corroborating the importance of Standing
  - Send Pictures and videos of your trials- especially helpful with powered mobility
  - Sometimes it is one particular part or piece that they do not cover
    - Talk with your ATP and see if you can pay for that piece outside of the quote

**Always Appeal a Denial- take it to mediation if necessary!!!!**

# How to fund equipment not covered by Insurance /Medicaid

- Adaptive trikes, Adaptive swings, Adaptive seating ( not wheelchairs), Van modifications, Bathroom modifications, etc
- **Community Living Assistance & Support Services (CLASS) waiting list can be 10+ years – apply as soon as possible**
- Vision programs in Texas :Blind Childrens Program can provide \$\$ for children who meet eligibility requirements ie CVI these \$\$ can be used for toys/equipment/switches/etc
- Social Security Disability- for those who qualify- income based
- Grants programs for Bikes /trikes, even adaptive motorized toys



# Funding Resources continued

- Look for places to donate and trade equipment
  - Donate any equipment you have outgrown- I love used equipment
  - Talk to Manufacturers Reps they have demos they sell really inexpensively when the new model comes out
  - Find places that will give you what others have donated and take what you are willing to donate
    - Austin it is CPathTexas.org
    - Houston area Terry Blessing runs a program 281-682-6296
- +sometimes organizations ie PTFK Warriors ( protect TX Fragile kids)/facebook groups will post ‘I have” “if you want” These parent groups can be great resources of information

# Case Study- Connor

- I met him when he was One year of age as his new ECI PT. He was undiagnosed had normal MRI, normal birth delivery, no trauma. He had no head control, he wore a helmet (plagiocephaly/torticollis), no trunk control, could not roll or lift head in prone. He had hypotonic trunk and very athetoid/dystonic in arms and legs. He was not weight bearing on his legs and was not able to sit at all. He could not reach or grasp, vision was a chronic upgaze. Did not use lower visual field. He was in a regular daycare. He had no positioning equipment. He did have a yoga ball.



Connor age 2.5 year  
Athetosis movements  
Hypotonia underlying  
tone



# 100's of Steps to making progress

Equipment loaned initially- stander and a kidkart wheelchair for positioning, also a floor sitter like the tumbleform chair with tray, helped family get- AFO's, and different hand splints

He hated standing initially- had to be bribed with TV, music, singing went from 10 minutes to 2 x 1 hour per day over a 6-9 month period of time his head control improved gradually with his standing program.

Lots of therapy ball time and therapy PT, OT, ST

- Began process of trialing equipment: we trialed standers, seating options
- Ordered him a Stander, Wheelchair, bathchair, and eventually a gait trainer when he was ready. He also has the floor sitter with tray at home- donated to family by therapist
- Assemble your team- he began attending a daycare for children with special needs, (daycare had identical equipment as he had at home) His parents were active participants, PT, OT, Speech all with ECI ( finally) at 2 years 4 months we called in outside Communication specialist
- IFSP- to include team time to meet all together to work on his unique needs PT 4x 60, OT 6x 60, Speech therapy 8x 60, Team therapy ( PT< OT< SLP )1x month for 90 minutes



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We trialed 3 different gait trainers  
He uses gait trainer without his  
AFO's on



Mom created awesome  
activities for him ie easter egg  
hunt, putting toys up on walls  
and doorways, loved rolling  
downhill on the driveway,  
playing in the sprinkler, racing  
in the hallways at daycare





# 100 steps continued

- He had multitudes of goals including feeding, swallowing, hand skills, head control, trunk control, standing, walking using gait trainer, eye gaze, positioning equipment usage etc
- Lots of things happened before we could look at assistive technology
- He had to have a stable place to work that was consistent
  - ( wheelchair and stander)
- He needed switches/power link, switch toys, and devices to trial
  - We needed consistent Access site: hands, head, eye gaze, legs?
- He had to have a consistent team that included his parents/teachers at daycare as well as PT, OT , SLP
- He had a low tech picture system that mom/teachers and speech therapist had put together
- Brought in consultant to trial different types of communication devices





We tried :  
head switches  
Hand switches L R and  
midline  
Foot switches  
Leg switches  
Round switches, light  
switches, things that  
provided auditory  
feedback, etc  
Mom and dad were  
focused on  
communication device  
\*Eye gaze





# Current UPDATE!!

- He now has his own eye gaze device and using it to tell his mom he wants to go to toilet and other great things
- He is about to get a new gait trainer- he has outgrown his
- His mom has been home schooling him through COVID and next year he will start Kindergarten- in person Fall 2022
- He is a great candidate for powered mobility\*\*\*
- Family built a one story accessible home for Connor
- Remember : Parents are the only consistent member of a child's team throughout their lifetime- Historian, visionary, the Driver of the goals/dreams!!

# My Favorite Programs/Assessments for working with Severely Delayed Children

- Every Move Counts- Jane Korsten
- Project MOVE ( Mobility Opportunities via Education) Linda Bidabe
- Little Room- Lilli Nielsen-
- Engineered Classroom- Carol Goossens
- Snoezelen multi- sensory environments

# Thank you for your time and Attention

- Thank you to CACNA1A and DEE-P for hosting these webinars

- Our next Webinar in the series is

**Low Tech Solutions for children with Complex Communication Needs,**

Presenter: Amanda Luddeke MS SLP CCC

April 8<sup>th</sup> FRIDAY at 11:00 central time